S2E12 Rep Josh Turek Representing Iowans and the Disability Community

Mike Hoenig: Hey everybody, it's Mike Hoenig from the University of Iowa Center for Disabilities and Development. Iowa's UCEDD, or University Center for Excellence in Developmental Disabilities. Welcome to Disability Exchange, a podcast which focuses on centering and elevating the voices of people with disabilities, our families, and our advocates. We are very pleased to partner with the University of Iowa College of Public Health, Midwest Public Health Training Center to produce the podcast. And we really appreciate you having taken the time to join us today. We have a great guest, and we'll get to him very shortly. But before we do that, I'd like to turn it over to Lori to introduce herself.

Laury Schielder: Thank you, Mike. Hello, my name is Lori Scheidler and I am a practicum student in social work here at the UCEDD. And I'm also a mother of a child with autism and ADHD.

Mike Hoenig: Thanks. So now we get to the fun part of introducing our special guest for today. His name is Representative Josh Turek, and Representative Turek, first of all, I want to thank you for taking time out of busy schedule to spend some time with us

Josh Turek: It's my pleasure. It's an honor to be here.

Mike Hoenig: Thank you. I know a little bit about you because I read a lot about the legislature, so I know that you represent the Council Bluffs area. Tell us a little bit about yourself.

Josh Turek: Sure. I was born and raised in Council Bluff, Iowa. I was born with spina bifida, so been a lifelong member of the disabled population. Grew up to a large and poor family. Family and life certainly wasn't easy growing up with a disability and certainly being socially, economically on the poor end of things.

I was fortunate enough to be exposed to wheelchair basketball early in my life and ended up playing professionally overseas. Played professionally about 15 years in Spain and Italy, France, Australia along the way, played in four Paralympic games.

Won two gold medals in wheelchair basketball. I knew that my basketball career was gonna come to the end at the end of Tokyo 2020, which ended up being 2021 due to Covid. I wanted to enter the job market as prepared as I could, ended up finishing my master's degree and I was working for a company assessing and providing mobility devices, wheelchairs, power wheelchairs.

And it was in there that I ended up realizing the incredible amount of denials due to the managed care organizations. in further researching realized that we had never had a permanently disabled member of the Iowa House.

Josh Turek: As opposed to looking around and wondering who, who should do that I decided to run myself and knocked 14,000 doors and knocked doors every day for six months, seven days a week, and ended up winning my election by grand, total of six votes. [00:03:00] I'm really proud and honored to be the first permanently disabled member in the lowa House.

And it gives me great pride to be able to give the disabled population a voice and representation because it's well needed.

Laury Schielder: Wow. Josh you've come a long way. You realized that there was a need out there. Was there one defining moment though that really made that jump for you to go into legislator?

Josh Turek: Yeah, I had always been peripherally interested in politics and especially living abroad, just seeing the differences in public policy and what. Government could actually do in terms of social safety nets or healthcare, living in Europe versus living in America. I did have that one moment, I was working out of muscular dystrophy and ALS, Lou Gehrig's Disease Clinic. And we were seeing about a thousand percent increase in the denial rate for mobility devices, both in power wheelchairs and manual wheelchairs. These are individuals that don't have time for denial rate. it just really struck me that we have to have somebody out here to fight for this.

And here we are in the disabled population with a higher percentage, of population than the African-American community where they have congressmen and senators and even a president, mayors governors. and yet we don't even have representation that was my aha moment.

Mike Hoenig: That is so interesting. I remember one time several years ago that somebody, I don't know if he broke his leg or something, but was in a real wheelchair temporarily. And there was a fire drill, or maybe a fire at the capitol. they had to figure out how to get him to a place of safety and So that was maybe the first introduction that several people had to disability. But I'm curious now, so are you a wheelchair user?

Josh Turek: I am, yes. Full-time

Mike Hoenig: Okay, cool. So how have you had to work with the Capitol, or have you been able to work with the Capitol to get some modifications made this year?

Josh Turek: We are in the state of Iowa the great state of Tom Harkin, the primary sponsor of the American with disabilities Act. We are more than 30 years post ADA and the Iowa Capitol was still not accessible. With me going in there, we finally have had automatic door openers added to every single door. We have a ramp in the house chamber whether it's an elderly individual or permanently disabled adult.

Josh Turek: They have now been able to navigate the Capitol in its entirety. They've been able to go down into the well in the house chamber. They see me in there. They see

somebody with a physical disability. We have somebody up there fighting for us, that we have representation, we have a voice. And that gives me a lot of pride.

Laury Schielder: I think we're really fortunate as a state to have someone like you to have the strength to take that move, and to make a difference When you were running for office and going through this process, did you have any naysayers or barriers in that process?

Josh Turek: I think the biggest naysayer was myself, I think oftentimes you can be your own biggest critic and you can second guess yourself. In terms of actual barriers, certainly there's significant. Thankfully I'm fit and I'm strong and luckily my level of disability is low enough that I'm active and agile. But probably the biggest barrier for myself, not only, but for any future individuals to want run, want to run for office is just the ability to interact with individuals and knock doors. Like I said, I went out and knocked doors seven days a week for basically six months. I knocked every single door in my district, because we have these very large hills.

There are stairs on every single home. It's just a matter of is there two or three or four or is there. 20 or 30. And that is an enormous barrier And yes it's a significant more burden for me. However, it was a blessing and a curse. It, I was far less efficient just because it would take me so much longer to drag my chair or scoot up the stairs to be able to speak to individuals. But it was also a blessing because the very first thing that people would ask me when they would see me up on their porch was [00:07:00] inevitably across the board, how in the world did you get up here?

And I would say, I crawled up here. I drug my wheelchair up here. And it didn't matter where they sat in the political spectrum, I found that people were. Willing to give me a handful of minutes after I drug myself up there to speak to them. After hearing my story and my background, but more than anything my motivations for running I, I feel like I was able to capture a lot of independence and certainly even a lot of individuals from across the aisle

Mike Hoenig: Oh, absolutely. I've been blind since birth, so I've experienced disability and discrimination all my life, and so I'm curious if you had any attitudes of, pity you poor kid, or anything like that when you knocked doors or have we gotten beyond that for the most part?

Josh Turek: That's a great question. I will tell you this I think there's a stigma related to individuals with disabilities and particularly a visible disability like mine in a wheelchair. I think that it comes in with a very low bar, And. Yes. I certainly think that my first initial interactions were oh, here's a [00:08:00] wheelchair member.

Josh Turek: Oh, this is cute. This is nice. What a great story. Sympathy. After a very short period of time of interacting with me they could tell that I was thoughtful and intelligent and educated and effective communicator, and they recognized that my motivations to address some of these issues like Employment within individuals with disabilities, healthcare, access to healthcare, reduction of pharmaceutical costs, improvement in education, aren't just issues that are related just to the disabled population, but these are issues that are related to everyone in the nation, But yes I think that initial stigma was there Chances are they aren't even familiar with my disabilities spina bifida or engaged a whole lot

with individuals from the disabled population. within the legislature, this is also a blessing and a curse One, I come with some level of credibility to be able to speak to the issues related to the disabled population, and I also believe that issues related to the disabled population is one of those issues that has the ability to rise above the tribalism.

That is the good part. The difficulty is not getting pigeonholed in to being strictly disabled legislator I feel a huge responsibility on my shoulders making sure that since I'm the first, that I do a very good job and that I'm constantly all alluding professionalism. And in being as well prepared as I possibly can because I don't want anyone to think that I'm in this position strictly due to some sort of charity case or people voting for me strictly because oh, whoa is me. This guy was in a wheelchair. I want them to know to definitively know that I earned this position out of: my resume, my hard work, my dedication, my level of intelligence my level of education things of that nature. And so it is, it's a heavy responsibility. But I promise you I'm working as hard as I can because I want to be certain that our 15% of the population, that we don't have one out of 150, but that I'm a trailblazer, so that eventually we have 15 out of the hundred. And on the Senate side, we have, 8 out of the 50 because that would be a true representation of the society that we live in.

Laury Schielder: Josh, I have to say I've had the pleasure of meeting you in person, I immediately knew you were someone of strength and intelligence within that minute, Where did you gain that ability to present yourself so well? If we were talking to our listeners, what words of advice could you offer someone to have that same demeanor and presence that you have?

Josh Turek: It's a great question. As I mentioned in the beginning, I think two things. First is I truly believe that struggle builds character. I grew up very poor. We shared clothes, had the wrong colored lunch tickets, oftentimes didn't have enough food. And then being disabled. I actually, I was bullied so bad that I ended up leaving public school and going to a small private school.

I think sometimes those sort of situations can end up breaking an individual, but for the ones that it [00:11:00] doesn't break, I think it. It builds this real deep character and belief in yourself. I know what real struggle is. And it gives you a superpower of, I don't care what you say or what you think about me, I know what I'm doing.

I know my motivations and I'm not gonna worry and the second is, It's just coming from high level sports and training for the Olympics. I absolutely believe is the very best preparation for politics. One is just the discipline, the dedication, the hard work. I threw everything into this the same way that I did with training for wheelchair basketball.

And it was cumbersome. It was certainly not easy to go out there and knock doors every single day. But it, it comes from that of, Just that ability to focus on the work, be able to tune out all the external noise, because there's a lot especially in this place. You can go on my Facebook or go on Twitter, it can really affect you emotionally or your mental health.

I don't worry about that. and I never did with basketball. It's, I'm going to just focus on the task at [00:12:00] hand, focus on the work. I know why I got into this. I know what my motivations are and I know where to put my time and energy in. And I think that was what did it is growing up, dealing with that struggle early on in life.

Mike Hoenig: You have to steel yourself from all the criticism.

Josh Turek: Yeah I insulate myself from that to a large degree, truthfully and again, some level of that is just self protection. I know where my time and focus needs to be. This job is incredibly time intensive. I have a brand new respect for legislators in a very short period of time of doing this. Most of the days during the session, I'm leaving to go to the Capitol around 7:30 or 8:00. Often times, I'm getting home at 9:30 PM it's really labor intensive.

There's not a whole lot of a financial incentive either. I always make the joke that this is the best, worst job in the world. I've never worked harder. I've never been paid less but I've also never been happier and more fulfilled.

Mike Hoenig: I know as a freshman legislator that you've been very active Could you talk to us a little bit about some of the bills that you've either sponsored or [00:13:00] supported?

Josh Turek: Sure. Yeah when I ran, my primary focuses was just to support public education. Also, as I had mentioned Increasing access to healthcare and reducing healthcare costs, reduction in pharmaceutical costs, supporting labor in the middle class and increasing the minimum wage.

I did, I put forth a bill that would match what Nebraska's done with their minimum wage. I did a bill that would match Disabled veterans to match their level of disability to their level of reduction of their property tax. A bill that would mandate that public schools have at least some form of disability awareness slash anti-bullying education. Very important as we have Black History Month and a variety of other minority groups that get some level of focus.

Education is ultimately the solution. If kids are aware, it takes the stigma away from it. it's a great bill, a fantastic bill, and hope we can traction. My two Magnus Opus bills: The first is a ban on cancerous carcinogens in catheters. And for those of us that are permanently disabled especially spinal cord injuries, a lot of us are using catheters multiple times on a daily basis.

And sadly, in this country the D E H P, which is banned all around the world, banned in the EU, even banned in this country, in water bottles and children's toys It is not banned. In a plastic that we are putting inside our bodies

Due to that, we've got just an epidemic of bladder cancer rates within the disabled population. Bladder cancer is one of the most cost-intensive forms of cancer to treat and we're paying for it the human loss of life. It's just egregious. And the last bill is my work.

What I'm calling a Work Without Worry Bill. As a lot of us know here in the state of lowa, we're running about a 17% employment rate for individuals with disabilities. We have a huge amount of the population of disabled individuals that have master's degrees, doctorates, bachelor's degrees, that are ready and willing to work, would love to work, but the only way that they can have certain types of healthcare is through Medicaid.

It's presenting us to have a huge amount of our population, and it's just forcing poverty amongst our population too. Almost like what was happening to the elderly population, presocial security. How in the world can you take a whole entire segment of the population that they've been limited to, making only \$16,000, \$15,000, some cases, \$20,000 a year, and then somehow just magically, suddenly make \$60,000, \$70,000, \$80,000, \$90,000 and live independently. It can't. So we have to provide them a guide way to be able to have independently living.

And ultimately, all of these individuals are on Medicaid. So unless we provide them a pathway, To getting away from this. They're gonna be on the system forever I really believe we'll be able to get this one done too.

Mike Hoenig: That should be a no-brainer.

Josh Turek: Certainly.

Laury Schielder: I think that bill that you just spoke of, Josh gives people, it would give people incentive to improve themselves, whereas right now they're better off just staying at status quo. And I agree that does cost us more in the long run.

Mike Hoenig: And it's not a life.

Josh Turek: In the end, we're just providing individuals an actual life with independence and be gainfully employed. This would be an opportunity for them to actually join the workforce, pay into taxes, and pay into the system because the only hindrance is just their healthcare.

Mike Hoenig: Exactly. We were at a point of needing to wrap up. I wanna take a minute of personal time. Josh, just to say this has been very motivational for me. Laurie, you mentioned a couple times that you had a chance to meet with Representative Turek and so I know that you visited center for Disabilities and Development and really we wanna thank you for taking the time outta your schedule to do that.

Josh Turek: Honestly, it's my pleasure. This is the main reason why I ran, and it's not only to be a quality representative for my constituents here in Council Bluffs and Carter Lake, but genuinely just to be a voice for us in the disabled community, because it was well needed. I genuinely don't believe that a lot of the situations we're dealing with, whether it's in, relation to healthcare or in relation to.

The employment numbers, I don't think it's being done out of malice. I think to a large degree it's being done out of lack of awareness. And so it's great to have an individual with a visible disability in the wheelchair there. So I'm excited about that.

Mike Hoenig: Absolutely. So what's your superpower?

Josh Turek: If I have one superpower, I told you it's the ability to tune out the noise and not necessarily care or worry about what people say about me. That's my superpower.

Mike Hoenig: That's amazing and a good one.

Josh Turek: Yes. Especially in the space I'm in now, because there's a lot of external noise.

Mike Hoenig: There is. Listening to you speak about these bills, I can feel the energy and I think you are gonna be a light for the state of Iowa

Josh Turek: I appreciate it. If I could say one thing to end this. It would be that it's really important for us in the disabled population to be collective and to be unified. Again, we're at least 15% of the population. That percentage is enough to swing any election. Go out and vote. Go support a candidate that you know is going to be behind the issues that are important to you. And we need to do a better job of making our voice heard let's make sure we're all rowing in the same direction and make our voice heard.

Mike Hoenig: You know what? I really love that message.

Josh Turek: We just want to again say thank you so much to Josh for taking the time out to be with us today. We'd like to thank our colleagues at the Midwest Public Health Training Center, send a special shout out to Joanna for recording and helping us keep things straight and most of all, to you our audience for listeners and stay tuned for more disability exchange episodes Thanks everyone.